

Working with professionals

A guide for families of children with developmental disabilities



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I Working with professionals

The SC Department of Disabilities and Special Needs continuously strives to help all South Carolinians with disabilities in meeting their needs and in achieving their possibilities. It is with these values that the agency provides services:

- a commitment to preserving the health, safety, welfare, dignity and respect of consumers;
- dedication to supporting family friends and community connection; and
- a tailored approach to each individual's situation, implementing state-of-the-art practices.

In keeping with South Carolina's plan of designing and coordinating services to put families first, the agency's services foster individual and family responsibility, consumer choice and opportunity, self-sufficiency and family independence. Services are customized to be responsive to needs, efficient, practical, appropriate and results oriented. Consumers and families are encouraged to participate in planning their services and supports, making decisions and advocating for themselves.

This guide is a tool for families of children with disabilities to use in helping their child to become more independent, responsible and achievement-oriented. It was written by a professional at the agency who has a child with mental retardation. It is based on her personal and professional experiences.



II

Learning that your child has special needs

When we, as parents, learn about obstacles to our child's development, the information comes as a tremendous blow. One mother described her experience as entering a dark tunnel with little hope for the future.

Family experiences are unique, but families often have common questions when learning of their children's special needs:

- What caused my child's disability?
- Did I do anything to cause my child's disability?
- What did I do to deserve this?
- How could God allow this to happen?
- What will my child be able to do?
- Will my child need support forever?
- Who will take care of my child when I am gone or too old to care for him or her?
- How will my child's disability affect my marriage?
- How will my spouse, my other children, my family and friends accept this child? Will they love my child?
- Will I be able to provide for my child's needs?
Will I be a good parent?
- Can I love this child?
- Will my child outgrow these special needs?

When learning that your child has a disability some common reactions include:

Denial

"This cannot be happening to me, to my child, to our family."

Anger

Aggression toward the child, professionals or family members.

Fear	Suspicion of the unknown and future
Guilt	Concern about what caused the problem.
Confusion	Not fully understanding terminology or events. Confusion results in the inability to make decisions.
Powerlessness	Inability to change what is happening.
Disappointment	Imperfection poses a threat to their sense of self and values.
Rejection	Rejection directed at the child, personnel or family. Some parents report a "death wish" for their child.

It is important for families to identify all feelings that can arise, so that they will know that they are not alone

What is different about parenting a child with special needs? Nothing really. Your child - like all children - needs love, understanding, security, discipline and care. You may need more energy, patience, understanding, stamina, know-how, assistance, financial resources, time and emotional support. At times, you may feel more stress, isolation, guilt, inadequacy, helplessness, despair and pain. Putting these factors aside, there is a great deal of joy in parenting a child with special needs.

Crisis and change are a basic part of all people's lives. How we deal with events, determines whether we feel defeated or stimulated to grow. While we may have little control over crises that come our way, we have the freedom to choose how we will respond.

Every person and family has strengths. Sometimes we are not aware of those strengths, because we are too busy dealing with everyday crises. We need to recognize our strengths. Then when problems mount, we can use them to handle situations more effectively. Here are some things you can do to help your perception of your family's strengths:

- Keep in touch with reality. Recognize that there are things we can change and others we cannot. When problems occur, many people see life through a single portion or slice only. Develop a broad outlook.

- Refuse to be a victim. After being confronted by problems, some people think that they are unable to solve problems or manage events. Consequently they become passive and tumble into depression.
- Look at change as a challenge. Those unwilling to accept change and view it as a challenge will find themselves frustrated or even broken.
- Focus on strengths, not weaknesses. Concentrate on potential, not limitations.
- Try not to compare what your child does with what others can do. Look for and appreciate your child's own strengths and contributions.
- Chose to grow. Every problem brings the potential for growth. We should approach challenges creatively and turn them to our advantage.
- Balance self-concern with concern for others. Personal healing comes as a result of helping others. Reaching out with compassion allows you to stay engaged in life.
- Maintain a sense of humor. Laughter is a good way to release negative tension.
- Talk with your spouse and other parents. Focus on gaining strength from each other and growing together. List your child's and family's strengths. You may be surprised at the insight others bring.
- Take care of your self so you will have energy for all the things you must do. It's easy to neglect you own needs. Ask your service coordinator about respite services and parent support groups.
- Turn to others for support. We know that people who have the support of others, whether in a formal or informal group have a positive outlook on life.
- You aren't the only one who can care for your child. Share caregiving tasks. Recognize others as an important part of your life.
- Think of reasons you appreciate each family member.
- Call your local disabilities and special needs board. A service coordinator will work with you to identify your family's service needs and resources available to address those needs.
- Explore support groups and publications related to your child's needs. Your service coordinator can help you find a parent support group and other resources in your community.
- Take one day at a time.
- Learn the terminology regarding your child's special needs. If

you don't understand what a professional is saying, ask for an explanation in simple terms.

- Seek information.
- Don't be intimidated by people involved in treating or helping your child. Ask questions. Seek second opinions.
- Don't be afraid to show emotion. It's ok to cry.
- Learn to deal with bitterness and anger.
- Remember time is on your side. Time may or may not heal wounds, but it does lessen the pain.
- Avoid judgment. Many people react to serious problems based on a lack of understanding, fear of not knowing what to say, or fear of the unknown.
- Keep your daily routine as normal as possible.
- Remember this person is your child, first and foremost. Your child's disability does not make him less valuable, less human, less important or less worthy of love and parenting.
- Let go. Throughout life letting go is probably one of the most difficult, but most important, things to do - day in and day out. You cannot control life. You cannot control each and every aspect of your child's life. Each child has his or her unique personality, and wants to live his or her own life.
- Avoid over indulging your child. Give your child opportunities to learn at an early age and don't protect him or her from challenges. Let children make mistakes and learn from natural and logical consequences.
- Avoid the punishment trap! Punishment can stunt your child's ability to become a self-reliant individual. Constant use of negative reinforcement will lower your child's self-esteem. Reward good behavior and use mild punishment such as behavior penalty, frank discussion about behavior, etc. Seek counseling and resources on proven ways.
- Encourage your child by talking about capabilities and weakness, provide opportunities for independent learning.
- Recognize that you are not alone.

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Stressful periods for families with special needs

As we all grow into adulthood, so do people with disabilities. Quite often, however, the developmental stages of your child with a disability do not coincide with those of friends. These differences may cause stress or concern for you or your family. These developmental stages of life include:

Differences in Expectations for a Child's Development

- Beginning to walk (12-15 months);
- Beginning to talk (24-30 months);
- Beginning public school (labeled as different in classroom);
- Puberty (tension between physical appearance and ability, sexuality, fear pregnancy);
- Twenty-first birthday (symbolic of independence, employment);

Differences in Expectations of Parenting

- Diagnosis of mental retardation or related disabilities;
- Younger siblings surpass your child developmentally;
- Serious discussion of placement outside the home or actual placement;
- Behavior or health problems unique to your child's special needs;
- Serious discussion of about guardianship and long-term care for your child.

Source Adapted from:
Chronic Stresses of Families
with Mentally Retarded
Children, by Lynn Wilker

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IV

Developing partnerships with professionals

Parents and professionals have different relationships with people who have disabilities. A parent's relationship is personal, lifelong and caring. A professional's involvement is time-limited and objective. Neither relationship is better; they are different. As with most partnerships, bringing people together with different skills and perspectives can create a successful team.

To form effective partnerships between families and professionals, there must be mutual respect and joint decision-making, sharing of feelings, flexibility, and honesty. Professionals and families work together to build capabilities. The challenge faces us all.

Key points for developing partnerships:

- Seek out professionals and parents who demonstrate concern for you and your family through their actions.
- Learn about normal child development, the nature of your child's disability and possible implications for your child's development.
- Learn your rights and the rights of your child regarding:
 - service eligibility;
 - confidentiality and access to services and supports;
 - informed consent and decision-making;
 - grievance procedures and rights of appeal;
 - policies, principles and standards for providing services and supports.
- Keep a record of all contact with professionals and agencies. Include the date and type of contact, the person's name and title, telephone number (and address when necessary), a summary of important points discussed and details worth recording.
- Develop a file of all material related to your child's development, and services and supports.
- Keep copies of all information you gather or provide.
- If access to a professional is difficult:

- discuss your expectations for access with the professional at the outset.
 - request to meet by a certain date and specify how much time you think you'll need.
 - let him know you have problems reaching him and ask what to do to avoid delays.
- Tell the professional what kind of help you or your child want, if you can. If you aren't sure what kind of help you want, let the professional know you reserve the right to decide later.
- Tell the professional you and your child want, and expect to be involved with decision-making. Anticipate upcoming decisions and make sure you and your child are involved.
- Be responsible for your child and for advocating in your child's best interest.
- Know about the resources available to you and your child. Be specific with your service coordinator about your child's and your family's needs.
- Learn about admission criteria and service goals of all relevant agencies.
- You are your child's best advocate; collect information, stay involved and participate.
- Before meetings write down points to be discussed, questions to be answered and decisions to be made.
- Be on time for all meetings. You may want to make notes of your discussion.
- When scheduling meetings with professionals, clarify the date, time, place purpose, participants and whether you need to bring materials. If you feel unsure about attending a meeting, arrange for another parent or advocate to go with you. Consider meeting at a neutral site, if your setting or the professional's setting could adversely affect decision making.
- After attending meetings and conferences, record the date and place, names and affiliations of all participants, information discussed, decisions or disagreements, and the date and details of any future meetings.
- Make sure all commitments include a target deadline and identify the person(s) responsible.
- Remember professionals are people who choose to provide services and supports of a particular nature. For this exchange to be useful, the professional should be a resource to you and your family.

- Develop relationships with professionals before you need them.
- Believe that all problems have solutions. Allow time to help. Don't give up
- Remember - you and your child are the final decision makers.

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Resolving conflict

You may be angry if you don't think that your needs are being met or that professionals are working on your behalf. Take time to discuss these concerns with professionals.

If you and the professional disagree:

- a . Focus on your child's best interest.
- b . Emphasize what's right rather than who's right.
- c . Begin with areas of agreement and work from there. When your views of "reality" differ, explore both views to understand each other's concerns.

Separate the people from the problem. Problems frequently fall into three basic categories: perception, emotion, and communication. If perceptions are inaccurate, look for ways to educate. If emotions are running high, find ways for each of you to let off steam. If there are misunderstandings, work to improve communication.

Don't let anger and frustration affect your relationship.

Perceptions

How you see the world depends on where you sit. People see what they want to see. The ability to see situations from another point of view can help solve problems. Understanding the other person's point of view is not the same as agreeing with it.

One way to deal with differing perceptions is to discuss them openly, without blaming anyone.

Emotions

Recognize and understand the professional's emotions, as well as your own. Why are you angry? Why are they angry? Are they responding to problems from the past?

Talk about everyone's emotions. A good way to deal with anger is to release your feelings by airing concerns.

Communication

Communication is important in resolving problems. There are three basic communication problems:

- a .** Not talking to each other.
- b .** Not hearing each other.
- c .** Not understanding each other.

What can be done about these three communication problems?

- Be a good listener. Pay close attention to what is said and ask the other person to say exactly what he means.
- Make sure that the other person understands you.
- Speak for yourself and your child, not for the other person. Tell how the problem affects you and your child.
- Be knowledgeable

If you honestly have tried to resolve your differences with the professional and still believe that he is not meeting your expectations, go to the supervisor and discuss your concerns or request a second opinion.

If you still are not satisfied after meeting with an individual's supervisor, request a copy of the agency's grievance procedures and rights of appeal.

Usually, if you and the professional mutually discuss your concerns and work to resolve them, grievance and appeal procedures will not be needed.

Preventing Problems

The best way to handle problems is before they become problems. Build a

working relationship with professionals. Get to know them personally.

The next chapter will discuss ways to build effective partnerships with professionals.

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VI

Involvement

To develop effective partnerships, parents must be actively involved in essential aspects of their child's development and individual plan of support. Parents, family members, friends, neighbors, service coordinators, and sometimes other provider staff need to work together in forming the child's circle of support.

These individuals agree to meet on a regular basis to help your child accomplish his or her aspirations and goals. They work with your child to open doors to new opportunities, overcome obstacles, provide supports and take action on behalf of your child. Individuals forming your child's circle of support are volunteers. They care about your child and are committed to work together on behalf of your child.

If your child lives in a residential setting, you still need to be involved. You should purchase your child's clothing, and personal items, participate in plan of support meetings, monitor your child's progress and discuss future support needs.

You can also become involved as a volunteer by joining the consumer / family organization of your local disabilities and special needs board, or your school's parent / teacher organization and other local advocacy groups. You can participate in these organizations as an advocate for individuals with disabilities.

Here are some other ways to become involved:

- Serve on your local disabilities and special needs board

consumer review team to monitor the quality of services provided by the board;

- Help other parents by participating in support groups, family organizations, etc.;
- Serve as an advocate for another individual with a disability who does not have a family member to advocate for her;
- Assist in fundraising activities for special projects or needs;
- Promote public awareness to state and local government officials, as well as the news media and public, regarding disabilities and special needs;
- Attend your local disabilities and special needs board meetings and provide advice to the executive director and board members on service delivery, gaps in services and the quality of services provided

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VII

Helping children become independent

As parent juggle the demands dictated by their young child's disability, planning for that child's adulthood may seem overwhelming. Yet with modern medicine and technology, most children with disabilities become adults. Parents need to plan for their future as they would for any child. Children need to learn to make choices and decisions. This is even more important for children with disabilities.

A successful transition from childhood to adulthood begins when children learn about themselves, realize their strengths and weaknesses and begin to value themselves. It ends when, as adults, these same children make choices and decisions which impact their lives and they take responsibility for their actions. This is called self-determination.

For children with disabilities, families and professionals may need to extra responsibility to ensure that this process occurs. Children learn many of the attitudes and abilities leading to self-determination by watching their families. Experiences teaching these lessons must be intentionally provided to

children with disabilities and not left to chance. Here are ways that families can play a critical role in teaching their son or daughter self-determination:

- Walk the tightrope between protection and independence. Allow your son or daughter to explore his or her own world. It is never easy, but all parents have to "let go."
- Children need to learn that what they say or do is important and can influence others. This means allowing risk-taking and exploration. Encourage your child to ask questions and express opinions. Involvement in family discussions and decisions-making sessions is one way of providing this opportunity to learn.
- Self-worth and self-confidence are critical factors in the development of self-determination. Model your own sense of positive self-esteem to your child. Tell your child that he or she is important by spending time with him or her.
- Set realistic but ambitious expectations. Take an active role in your child's educational experience.
- Recognize the process of reaching goals - don't emphasize only outcomes. Children need to learn to work toward goals.
- Don't run from questions your child has about his or her disability. Stress that everyone is an individual, encourage your child's unique abilities and help him or her to accept unavoidable limitations.
- Schedule opportunities for interaction with children of different ages and backgrounds. This could be in day care centers, schools, churches, and when playing in the neighborhood.
- Allow your child to take responsibility for his or her own actions. Provide valid reasons for doing things. Providing explanations allows the opportunity for your child to make an activity his or her own.
- Don't leave choice-making up opportunities to chance. Take every opportunity to allow your child to make choices that are meaningful. Make sure your child's decisions are honored.
- Provide honest, positive feedback. Focus on the behavior or task that needs to be changed. Don't make your child feel like a failure.

The most important environment for a child with a disability to become self-determining is in the home. A child who learns self-worth from his or her parents is likely to become an adult who is self-determining. By being

allowed the opportunities to make choices and decisions, to explore and and take calculated risks and to learn form experiences of success and failure, your child can develop the abilities and attitudes necessary to live successfully as an adult.

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VIII Summary

"All of us have dreams, visions and anticipations for the future. Like everyone else, people with disabilities and their families have great expectations. Like everyone else, they too need help to be able to have their expectations come true. Professionals and other people without disabilities also need to have great expectations for people with disabilities. Great expectations include feeling control over one's life, a feeling of meaning in one's life, and a sense of one's own value."

All people bring important gifts to their community. This is true for people with disabilities, as well as people without disabilities. Too often, the positive contributions made by people with disabilities have been denied or ignored. We have focused on deficits and negative characteristics and overlooked the gifts and capacities of people with disabilities. People with disabilities have the ability and right to make contributions and people without disabilities have the right to enjoy the fruits of those contributions. It is for that reason that all of us should create the opportunities in which these contributions can be given and their expectations fulfilled.

We need to work together to build on capabilities, adapt environments, build relationships, help individuals and their families identify what is important to them, and empower them with decision making and spending authority to act upon those choices.

"Visions, dreams, great expectations - the challenge faces all of us. But only if all of us have great expectations for each other, especially for people with disabilities and their families."

Source:

***Families and Disability Newsletter, Volume 2, Number 1; Spring 1990,
Beach Center on Families and Disability***

Traditionally, the outlook for people with disabilities and their families was somewhat bleak. Today, families are no longer resigned to fate. People with disabilities are recognized and appreciated members of their family and community.

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IX

Parent's Bill of Rights

As a parent of a child with a disability, you have the same rights all parents have.

- The right to be blameless.
- The right to understand processes and procedures.
- The right to be free from exploitation.
- The right to make or refuse requests from others without feeling selfish or guilty.
- The right to accept help without an apology.
- The right to make decisions.
- The right to feel and express anger and other emotions.
- The right to feel healthy competitiveness.
- The right to make mistakes while learning.
- The right to ask others for consideration, help and / or attention from others.
- The right to tell others your needs.
- The right on some occasions to make demands on others.
- The right to request others on some occasions to change their behavior.
- The right to be treated as an adult and not be patronized.
- The right to not be doubted by others.
- The right to take time to sort out your reactions - not to be

pressured into immediate reaction.

- The right to be free of other's imposed values.
- The right to a normal family life.
- The right to live a part of your life without your child.
- The right to expect miracles.

Source:

Parent Education and Assistance for Kids, Colorado Springs, and Exceptional Parent, November/December 1998

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X

Commandments for families with special needs

It is important to maintain a well-balanced life in order to be effective in your child's life. These commandments can help you "stay on track" during hectic or difficult times.

- Thou shalt be thy child's best and most consistent advocate.
- Thou shalt share valuable information about your child with professionals who need your input.
- Thou shalt put it in writing and keep a copy.
- Thou shalt try to resolve problems at the lowest level but not hesitate to contact a higher authority if the problem isn't resolved.
- Thou shalt keep records.
- Thou shalt seek information when needed.
- Thou shalt take time to think through information before making a decision.
- Thou shalt have permission to be less than perfect. Important lessons are learned both from successes and failures.
- Thou shalt not become a martyr. Take a break now and then.
- Thou shalt maintain a sense of humor. It is great for your own

emotional well-being and that of your child.

- Thou shalt always remember to tell people when they are doing a good job.
- Thou shalt encourage thy child to make decisions because one day he or she will need to do so.

Source:

Virgina Richardson, Pacer Parent Training Coordinator

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XI Appendix

Perceptions of Disability

Traditional

People with disabilities are a burden to their family and society.

Families are dysfunctional because of the burden created by the person with the disability

Families should have low expectations, expecting segregated services and second-class citizenship, because it is unrealistic for them to expect integrated services.

State-of the Art

People with disabilities are valued and contributing members of their families and society.

Society's reaction to and policies about families and disabilities can create dysfunction in families.

Families should have high expectations and skills to obtain integrated services and full citizenship.

Family Roles

Traditional

Mothers are the ones most interested in services for the child.

Parents of adults are overprotective; so adults should be independent from their parents and rely upon professionals as family substitutes.

Siblings should take responsibility for long-term care of their brother or sister, both before and after their parent's deaths.

If any family member is severely "distressed" by the person with a disability, separation from the family is acceptable. The person with the disability should be placed outside the home.

State-of-the-Art

Every family should have the opportunity to designate appropriate members to take on various roles in the child's life.

Adults with disabilities have the opportunity to identify and act on preferences for family roles.

Siblings are entitled to normalization and their own lives. It should not be assumed that they will always have a major role regarding their brother or sister.

There are many appropriate ways to support families so they can provide a supportive home to all members, including the person with the disability. Ensuring the person with the disability has a wholesome family life is especially important.

Myths and Realities

Myth

Reality

Parents are too emotional.	Because of life experiences, parents who choose to participate in making decisions are nearly always realistic and knowledgeable.
Parents are too closely involved.	Because parents are so involved, they make effective decisions. They learn the system out of necessity and can help shape policies and services from their practical needs.
Parents are concerned only about their child.	Parents involved in public policy making have learned that in helping themselves they may help others.
Parents always want more.	Parents want some control over services for their child with a disability.
Parents don't understand or appreciate funding problems.	Parents are taxpayers and don't want to increase spending unnecessarily or irresponsibly. They are usually more sensitive to unnecessary expenditures.
Parents are troublemakers.	Taking part in decisions that affect the lives of family members is being responsible, not making trouble.
Parents expect too much.	Parents are aware that quality services can help children reach their goals. Approaching that goal for people with special needs is cost-effective, since

they need fewer services
as they gain independence.

Sources:

Supporting Families With a Child With a Disability, Alan Gatner, Dorothy Kerzner Lipsky, Ann P. Turnbull, Brookes Publishing Company, 1991

"The Speaker" , Newsletter of Sequin Retarded Citizen Association, 6223 West Ogden Ave., Berwyn, IL, 60402.

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XII

Helpful Publications

The SC Department of Disabilities and Special Needs offers the following publications free of charge for people with disabilities and their families. For copies of more information, call:

The SC Department of Disabilities and Special Needs
Office of Community Education
(803) 737-6477
V / TTY (803) 737-6474
1-888-DSN-INFO
FAX (803) 737-6323

Child Care and Development Block Grant Facts

- general information and eligibility criteria for the Child Care and Development Block Grant program.

Causes and Prevention of Mental Retardation and Related Disabilities: A Handbook for School and Community Programs in South Carolina

- handbook for professionals in community and school

programs describing major causes of mental retardation and related disabilities. Activities for prevention and additional resources are listed for each major cause described.

Choosing a Caregiver

- offers individuals and families tips on interviewing prospective caregivers and ways to help the caregiver become familiar with the family.

Claims and Coverage

- brochure about health insurance for families of people with mental retardation.

Consumer/Family Organization Manual

- guide to assist with the role, functions, development and organization of local consumer / family organizations.

Family Matters

- guide for brothers and sisters of people with disabilities and special needs that provides suggestions for helping them face unique concerns and challenges.

Head Injury: A Family Guide

- helps families adjust to living with a family member who has survived a brain injury. In addition to addressing relevant legal, social and vocational issues, the booklet advises families ways to create a new family lifestyle and ways to manage emotions and behaviors of the person with the brain injury.

Making Life Work After Head Injury

- includes medical information about brain injuries and what may be expected during the rehabilitation process. It also offers suggestions to help a person with a brain injury become reacquainted and active with family and community.

Medicaid Program Overview

- provides general information about the Medicaid program which provides medical care for people with low income.

Now...and the Future

- a guide to guardianship, wills, trusts, life and health insurance, government benefits, and other practical matters. The guide was published by the SC Developmental Disabilities Council, Office of Governor in cooperation with SCDDSN.

Practical Guide to services

- detailed information about programs and services available for people with disabilities. The guide also lists family support organizations, advocacy groups and other agencies which provide services to people with disabilities.

Publications Catalog

- list of brochures, manuals, standards, and other training materials published by DDSN.

Stork Service

- special support packet of printed materials for families of newborns with Down syndrome.

Tax in for Families of People with Disabilities and Special Needs

- general information about deductions and credits available to families of people with disabilities and special needs when filing state and federal taxes.

Working With Families Who Have Special Needs: A Guide for Professionals

- a guide to help professionals work more effectively with families of children with special needs. The guide outlines DDSN professional principles and philosophy, and includes responsibilities for providing family-centered services.

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Special Thanks

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